VOLUME 4, WINTER 2000 2003 INDIAN HEALTH SERVICE NATIONAL EPIDEMIOLOGY PROGRAM

IHS Epi News

Disease Rates and What They Mean

When we hear the term "rates," most of us think in terms of how much we get billed for our utilities. Epidemiologists, on the other hand, have a very different idea when it comes to "rates." The rates used by epidemiologists refer to disease rates that are calculated from data on the number of people with a certain health problem, such as lung cancer or food poisoning. Our first instinct is to use simply the number of people with the problem as a way to describe that problem in a community. Because we would like to put everything into perspective, however, we want to be able to compare one community with other communities.

For example, we might want to know how many cases of tuberculosis (TB) developed among American Indians (AI) in the state of North Dakota, compared to the number of cases developing among all other residents of the state. If we used only the number of people with TB, we would find that there were many more non-Indians with TB. Does this mean that TB is not a concern to North Dakota Indians? This is probably not a safe assumption simply because there are many more non-Indians than Indians in North Dakota and therefore there will be more non-Indians with TB. In order to compare the two groups, we need to calculate the TB rate in each group. In this situation, the TB rate is the number of cases of TB divided by the total number of people in the group, such as the number of AI with TB divided by the total population of AI in North Dakota. Because the resulting fraction is usually very small, epidemiologists routinely multiply it by 100,000 and refer to the rate as being "per 100,000 people." Once we have TB rates in AI and non-AI, we can compare the two rates and see if AI have more, or less, TB.

Most published reports of disease occurrence from state health departments or the Centers for Disease Control and Prevention (CDC) will list the rates at which the disease occurred. Such information is invaluable in identifying health problems and effective disease control or prevention efforts. If only our utility bills were as easy to understand. Below is a current activity involving cancer incidence rates.

Data Linkage Project:

The National Epidemiology Program is collaborating in a data linkage project that will lead to the first, ever, state-based estimates of cancer incidence for American Indian and Alaska Native (AI/AN) population in the US. Data linkage involves using information such as SSN, name and date of birth to identify the same person in the IHS patient registration database and in the cancer registry database. In the IHS data used for these linkages, a person is considered American Indian or Alaska Native by virtue of being eligible for - and having used - IHS services, and having a beneficiary code indicating that he or she is AI/AN. If that person links to a record in the state cancer registry and is not currently identified as AI/AN, that error can be corrected.

Such linkages have been conducted in the past but have not consistently resulted in updating the information in the cancer registries. The table below shows the extent of

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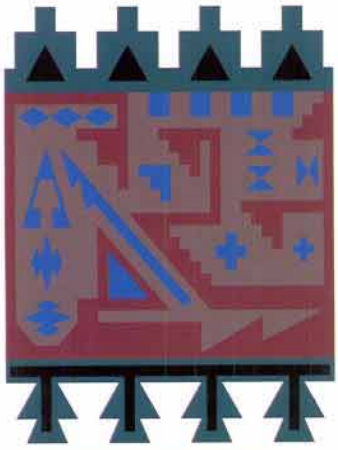


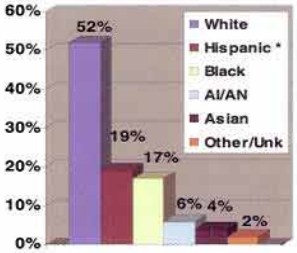
CDC's National Breast and Cervical Cancer Early Detection Program

NOTE: *On January 15, 2002, the President signed into law the "Native American Breast and Cervical Cancer Treatment Technical Amendment Act" which clarified that AI/AN women screened through the NBCCEDP were eligible for treatment coverage even if they are eligible for IHS or tribal health services. This Amendment supersedes the Breast and Cervical Cancer Prevention and Treatment Act of 2000 (BCCPTA - the Act)(Public Law 106-354) that amended the Title XIX of the Social Security Act to give States enhanced matching funds to provide Medicaid eligibility to a new group of individuals previously not eligible under the program. In essence, this allowed women, identified through the NBCCEDP, to qualify for breast or cervical cancer treatment, including pre-cancerous conditions and early stage cancer. This was effective Oct. 1, 2000, but questions arose regarding the eligibility of AI/ANs because of entitlements through other federal programs.*

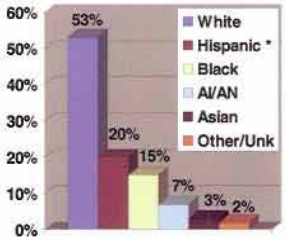
Recognizing the value of screening and early detection, Congress passed the Breast and Cervical Cancer Mortality Prevention Act of 1990 which established CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP). In 1993, this Law was amended to provide direct funding for breast and cervical screening services to AI/AN populations. There are twelve tribal entities currently funded by the CDC NBCCEDP. (Please see attached map.

To date, the NBCCEDP has provided more than 2.7 million screening exams to underserved women; including older, low income, and/or racial and ethnic minorities. According to data collected from 1992 to 1997 in a telephone survey, about 65% of AI/AN women aged 50 or older had received a mammogram in the last 2 years. In addition, about 82% of AI/AN women aged 18 or older had received a Pap test in the past 3 years. In both cases, older women were less likely to be screened. However, these figures are likely to overestimate screening rates for AI/AN women because the survey did not include women in households without telephones which were estimated to be about 23% of AI/AN households. The following charts represent the distribution of women receiving Mammograms and Pap Tests through the NBCCEDP, 3/31/2000. (Please see accompanying graphs.)

Mammograms by Race/Ethnicity, 1991- 2000 (N = 796,444)



Papanicolaou Tests by Race/Ethnicity, 1991 –2000 (N = 796,444)



* Includes Hispanics of any race.

In addition to directly funding AI/AN organizations, the CDC also funds the National Indian Women's Health Resource Center to provide technical assistance to tribal grantees and to states where AI/AN women are screened to increase outreach to these women. Also CDC-funded states provide support to AI/AN populations in a variety of ways to ensure that screening is available to Native women.

The total dollar amount supplied to the above organizations is $6,456,408 per grant year.

Public Health Prevention Specialist

This is the first year that IHS has had a Public Health Prevention Specialist (PHPS). The PHPS Program was developed by the CDC and is designed to mentor Master's level trained entry to mid-level individuals in public health and provide work experience in federal and state level governments. Ms. Yolanda Savage is that prevention specialist and will spend her two-year term with the IHS National Epidemiology Program.

"During my two year with IHS I will fulfill many competencies and participate in many activities, but my main charge is to implement the National Public Health Performance Standards Program (NPHPSP) in IHS Areas. This assessment tool is designed to assess public health infrastructure and capacity in state and local governments. To date, there have been 3 demonstration sites within IHS that have implemented the NPHPSP. Preliminary results have shown that public health systems within IHS operate differently from state and local public health systems. As a result of this discovery part of my two-year assignment will consist of adapting both the assessment tool and the User's Guide for use in AI/AN communities.

I am looking forward to my two-year field assignment! I plan to face every challenge and activity with diligence and hard work. Quote to live by: "He who can see the invisible can do the impossible.'" Please help us welcome Yolanda to our program and if you have any questions on public health assessment, give her or Dr. David Espey a call.

Colposcopy Program

The Colposcopy Program is offering another "refresher" workshop this year, March 5-7, in Albuquerque. This will be the tenth year that it is being offered. Tuition will be waived for IHS providers and those tribes that left their shares with the IHS Cancer Program.

The Basic workshop is still being offered in alternate years and will be offered again in 2004.

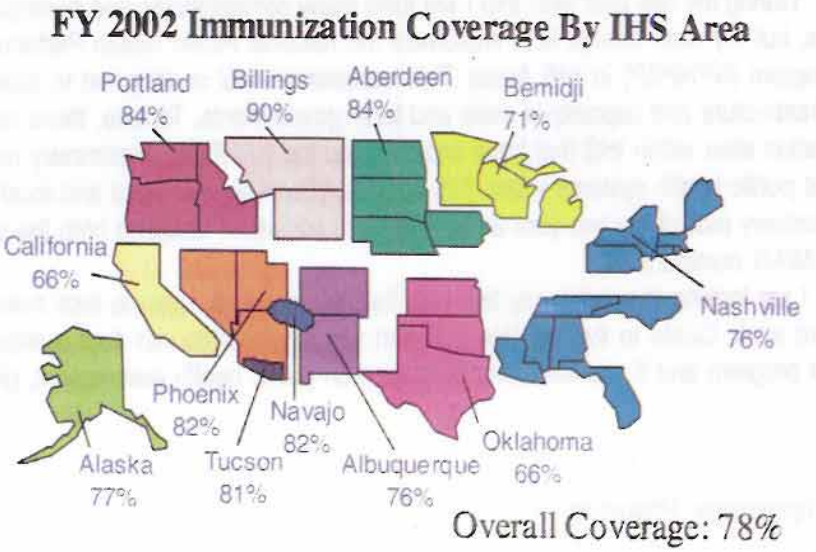
Both are still well attended and in demand. If you have any questions or interest, please give us a call.

Cancer Support Group Training

Training for AI/AN people interested in leading cancer support groups in their communities is still available. The training is 4½-days in length and the format consists of lectures/discussions, simulations and education materials. The ideal cancer support group leader will be a cancer survivor and/or family member or close friend who has shared the cancer experience. Reimbursement for travel, tuition and expenses is available for a limited number of people. For more information, please call the office.

Immunization Activities

Where to begin? 2002 was a busy year for immunization activities, and we have a number of projects underway for 2003. Here's a brief summary - if you want more information, contact Amy Groom at (505) 248-4374. First and foremost, CONGRATULATIONS to the Billings and Navajo Areas for their high immunization coverage levels. In March 2002, both Areas received an award at the National Immunization Conference in Denver for achieving immunization coverage levels of 90% in children, ages 3 - 27 months.



Immunization Assessments: In the spring of 2002, we worked with the Great Lakes Tribal Epidemiology Center and the Bemidji Area Office to conduct immunization coverage assessments at 9 sites - 3 in Wisconsin, 3 in Minnesota, and 3 in Michigan. We looked at records of children 2 - 6 years of age and assessed their immunization status. We also collected information on all clinic visits between 0 - 3 years of age for a sample of children to look at missed opportunities for immunization. The individual facility reports have been completed and sent back to their respective sites, and an overall report comparing all of the facilities is in the works. Stay tuned!

RPMS Immunization Package: A new version of the RPMS Immunization Package - Version 8 - is underway. Cimarron has been working with the Area Immunization Coordinators and key RPMS users on this update. Some of the main changes identified so far are:

1. **No more dose numbers** - you will not be required to include a dose number when entering a vaccine. In addition, the quarterly and two-year old reports will not use the dose number when calculating up-to-date coverage.
2. **The Two-year old report will be expanded to 19 - 35 months** - to allow use to compare our data to the CDC's national Immunization Survey data.
3. **Invalid dose field** - will be added so that doses can be labeled as "invalid" and won't be included in the forecast or the reports.
4. **Point-of-service data entry** - a program has been developed that will help eliminate orphan visits generated when immunizations are entered directly through the immunization package as a ambulatory visit.

We will also be providing 3 training sessions on the new package - no details yet as to where or when.

Immunization Data Exchange with States: We've all been hearing about immunization registries for YEARS now - but guess what? It's really happening! In order to make sure IHS and tribal facilities don't miss out on the benefits of these state immunization registries, we are creating a module for the RPMS immunization package that will allow IHS and tribal sites that are using the package to automatically exchange data with state immunization registries. The module is being piloted at IHS and tribal facilities in 4 states – AZ, UT, SD, and WI, and once the testing has been completed, it will be distributed to all IHS and tribal RPMS users.

Tobacco Control Update

During 2002, the Tribal Support Centers were busy attending meetings and training so they can provide tobacco control services to their tribes. During February, they were convened in Atlanta to assist with developing the program to conduct the Adult Tobacco Surveys (ATS) in 2-3 tribal communities. As a result, funds were made available to all six centers that applied. Currently, the ATS Project sites have been busy reviewing and revising the American Indian/Alaska Native (AI/AN) version of the ATS, developing consent and data agreement forms, and assisting with the IRB request which will be submitted to the Indian Health Service. After some pilot testing of the instrument, the six centers will be fielding the AI/AN ATS in their respective service areas during the summer of 2003. This is a first for the centers and for CDC!

The CDC-funded National Tribal Tobacco Prevention Network hosted its second annual Native Conference on Tobacco Use in Salt Lake City, Utah during July of 2002. This event attracted many participants from Indian Country, nearly doubling the figures from the first conference.

Finally, in December of 2002, the support centers' staff gathered in Albuquerque for 3 days of training. During the first morning, all attendees were certified at Trainer of Trainers for the American Cancer Society's Freshstart Smoking Cessation Program. Many thanks to the local ACS staff for conducting the training. During the training, Cynthia Coachman of the Muscogee Creek Nation's support center gave an update on how the Oklahoma ACS is adapting the Freshstart Program to accommodate the needs of AI/AN populations. This program will be called Second Wind and will be available for distribution in the near future. During the remaining days of the training, the centers' staff received enlightening and practical training on media production from a local American Indian film producer. Representatives from the CDC Office on Smoking an Health Communications Branch attended so they can facilitate the inclusion of AI/AN media resources at CDC. Many of the centers' staff thought the media training was "a lot of fun" and "provided many ideas for media development."

Tribal Support Centers' staff in attendance at the December meeting in Albuquerque, NM.

STD Program Activities

As always there are many activities happening on many different fronts. The following is a brief summary:

STOP Chlamydia: Revision of this program is currently underway. This includes enhancing data collection by eliminating unnecessary variables and automating the data entry and reporting process. The current data collections instrument is being reviewed by different providers. Participating facilities will be able to enter data through the Internet and will also be able to download automated reports.

National Network of STD/HIV Training Centers: An assessment of Provider STD training needs was conducted for approximately 65 providers in 14 different facilities at 10 different IHS Areas. The final report will be finalized in February 2003. Several Navajo IHS physicians will be piloting an on-line syphilis module developed by the Seattle PTC Training Center. An STD/HIV curriculum for non-clinicians working in a reservation setting is being developed similar to one already underway in Navajo. It is hoped that this can be replicated in other areas as well.

Navajo/Zuni Syphilis/HIV Outbreak Activities: The California STD/HIV Training Center is assisting to develop non-clinical training for CHRs, Health Educators, and Behavioral Health Counselors. Two projected trainings are Feb. 3-7 and Mar. 24-28, 2003. Dr. Thomas from UNM will be conducting a "How to do Risk History Taking" at the service units. With financial assistance from the AZ State Health Department, two IHS facilities in AZ will implement stat RPR syphilis testing.

WEBEPI: Non-traditional educational methods and on-site training are needed for IHS and tribal health providers unable to leave their work sites. One educational intervention, WEBID, is alreadybeing piloted in 5 sites.

The five project phases are:

- ◈ Identify local site coordinator
- ◈ Review indicator data for discrepancies
- ◈ Data validation through CDC
- ◈ Launch project at each site
- ◈ Module development - Dr. Thomas is reviewing and drafting new modules. You can review these on-line at: www.webepi.org/WebEpi/cme_toc.jsp

Participating sites and coordinators:

- ◈ W.W. Hastings - Raymond Rhoden
- ◈ Phoenix Indian Medical Center - Erica Avery
- ◈ Albuquerque Indian Hospital - Bill Gloyd
- ◈ Ignacio - Joan MacEachen &
- ◈ Rapid City - Carol Smith.

STD Clinical and Community Assessment Projects: Demonstration projects are being developed to identify effective disease prevention and control strategies in reservation and urban settings. Three Areas are interested: Billings, Aberdeen, and Alaska.

Regional Infertility Project: Work is underway with the Region VIII Infertility Project to automate Chlamydia laboratory reports. Web-based reports already developed by a SAS expert will be utilized to combat the labor intensive work of providing local reports for each site participating in the IPP.

Capacity Building Initiatives: Work with the Wellmart foundation to help with a community based health project in Pine Ridge has started. This initiative will be headed by a public health nurse to develop a community-based STD program.

STD Infrastructure Project: This project is being coordinated by the Phoenix Indian Medical Center through a contractor, Patty Hibbler. She developed a survey to investigate local IHS facilities ability to prevent and control STDs and syphilis in their service units. The first phase of this project is completed at 4 IHS facilities in Arizona.

Update on MRSA Study

The methicillin-resistant Staphylococcus aureus (MRSA) project in Rosebud, SD, which is aimed at helping us understand more about MRSA in the community, is still progressing! We finished enrolling participants into the project in October 2001. In total, we have enrolled approximately 500 people from over 120 households in Rosebud as well as surrounding communities. We'll soon be exploring what factors may be associated with MRSA in the community.

We'd like to thank the community for their support and interest in this project. Special thanks to the community health representatives, the Public Health Nursing Program, and the Medical Records staff at the hospital for helping us carry out this project. For more information, please contact Cheryl Mason at (505) 248-4226.

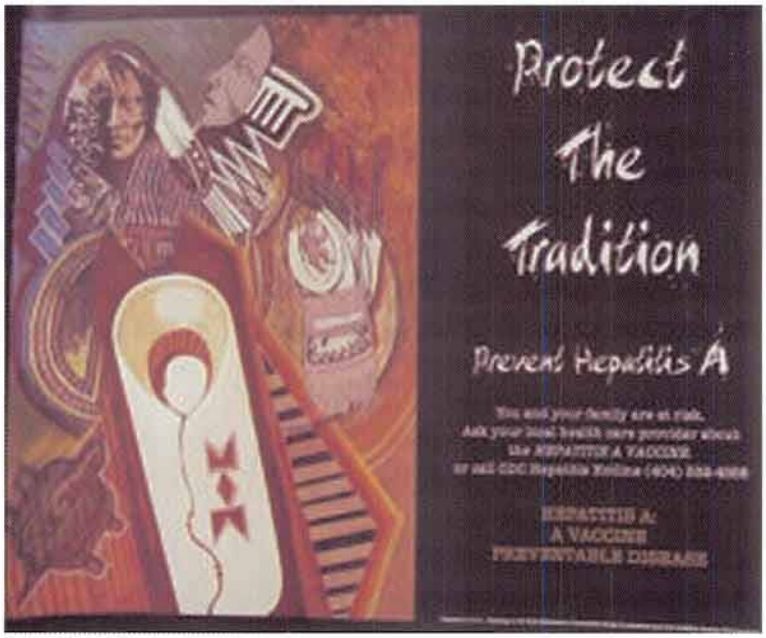
MRSA Outbreak and Investigation

In August the National Epidemiology Program (NEP) received a call from an IHS hospital that had detected a cluster of methicillin-resistant Staphylococcus aureus (MRSA) skin infections occurring in newborns. While the presence of MRSA has long been a problem in the hospital setting, in recent years it has been recognized more frequently in the community among otherwise healthy persons without the usual risk factors. These cases presented an interesting puzzle, as initial review of the clinical histories and microbiological results revealed characteristics of both hospital- and community-acquired infection.

Staphylococcal bacteria commonly live on the skin without causing infection, but when passed from a "carrier" to a susceptible individual via direct contact these same bacteria can produce infection. We sampled hospital staff that potentially had had contact with the infected infants to see if any were MRSA carriers. We also designed a case-control study and sampled household members of both cases and controls in an effort to determine if the infections might have been contracted or propagated outside the hospital. A single healthcare worker (HCW) who was strongly linked to the case patients was positive for MRSA. We used a very sensitive DNA fingerprinting technique called pulsed-field gel electrophoresis (PFGE) to compare this strain of MRSA to those that were available from the patients (7 of 9). All were an exact match, lending strong support to our hypothesis that the HCW had been the source of transmission. Oddly however, this strain did not match with known hospital-associated strains, but rather with a well-characterized community-associated strain. To our knowledge this has not been described before in a hospital outbreak, and illustrates that it is becoming increasingly difficult to differentiate hospital- and community-associated MRSA as the bacteria becomes established outside the healthcare setting.

We recommended that the HCW be excluded from patient care while receiving treatment to attempt to clear the MRSA. Treatment was successful, and there have been no further cases in the three months since the HCW returned to work. We further advised careful adherence by hospital staff to standard precautions and infection control practices, which remain the simplest and most cost-effective means to prevent hospital-acquired infections.

Hepatitis Program Activities



The Hepatitis Program has undergone some changes in the past year. Doug Thoroughman, the former CDC Division of Viral Hepatitis (DVH) field assignee, has moved on to the Kentucky State Department of Health and we wish him well.

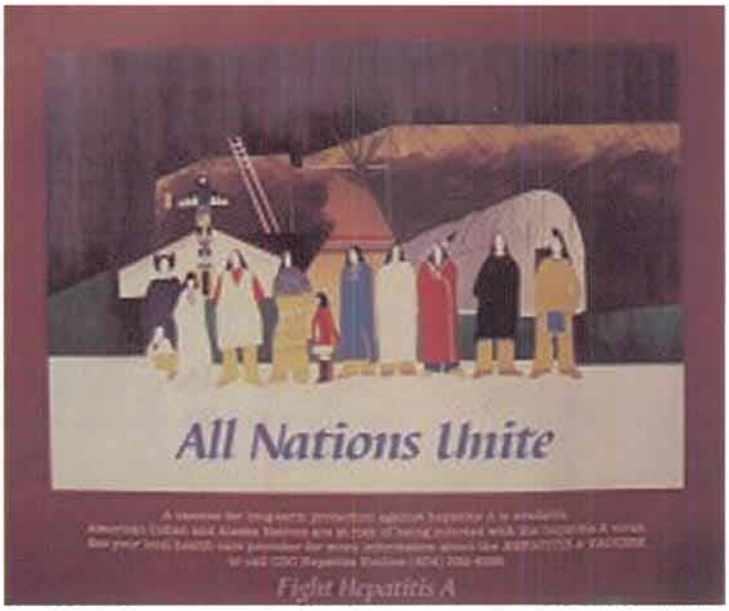
In July 2002, the National Epi Program welcomed John Redd, M.D., M.P.H., F.A.C.P. as the new CDC DVH field assignee. John previously spent five years as an IHS clinician at Shiprock and then another two years at the New Mexico Department of Health as an EIS officer.

In September of 2002, the Hepatitis Program expanded to include Cecile Town, M.P.H. as the new IHS Hepatitis C Coordinator. Cecile moved to Albuquerque from Honolulu, where she completed a field assignment at the Hawaii State Department of Health with the CDC Public Health Prevention Service. Her previous public health experience includes tobacco abuse and prevention with California tribal communities and motor vehicle injury prevention and viral hepatitis at the CDC.

The IHS Hepatitis Program is looking forward to the year ahead and welcomes participation from throughout IHS on its endeavors which include:

- Ø Working with three Viral Hepatitis Integration Projects (VHIPs) that focus on integrating screening, testing and vaccination for viral hepatitis into existing HIV, STD and detoxification/rehabilitation programs. These projects are at Na'Nizhoozhi Center, Inc. in Gallup, NM, the Phoenix Indian Medical Center and the Seattle Indian Health Board Thunderbird Treatment Center.
- Ø Developing educational interventions for IHS providers and patients.
- Ø Working on policy with the IHS HCV Workgroup that can impact standards of care in IHS with regard to viral hepatitis. And,
- Ø Epidemiologic research that will provide AI/AN specific data on the impact of viral hepatitis on our communities.

Hepatitis Program staff are also available to lead or assist with hepatitis-related outbreak investigations and vaccination and education efforts. John and Cecile look forward to working with others throughout IHS on viral hepatitis and encourage those with questions or potential projects to contact them. Phone: (505) 248-4226



CDC Update and Perspectives.....

This newsletter contains many examples of how the Centers for Disease Control and Prevention (CDC) and IHS are working together with tribal partners to address important public health issues in Indian country. CDC's commitment to these efforts is steadfast and growing. As of this writing, ten of the IHS National Epidemiology Program professional staff are CDC assignees, and two are contractors supported by CDC funds. Collaboration between our two agencies takes place on a number of levels, ranging from categorical, or disease-specific, programs to broader public health policy issues. Through the IHS/CDC/ATSDR Senior Policy Workgroup, a work plan is being developed to help link clinical and preventive health services, to foster tribal-state partnerships, to strengthen public health infrastructure, to enhance bioterrorism and emergency preparedness, to strengthen disease prevention and control programs, and to minimize the public health impact of hazardous substances. CDC/ATSDR and IHS are also actively participating in the Secretary's Intradepartmental Council on Native American Affairs (ICNAA), which will provide a venue wherein these issues and others can be addressed across the Department of Health and Human Services. The recent reactivation of ICNAA is just one example of the Department's support for, and commitment to, improving public health in Indian country.

Elsewhere within CDC changes have occurred that will be of interest to readers of this newsletter. CDC's new Director, Dr. Julie L. Gerberding, continues to demonstrate her strong support for improving the public health of Indian people. Within the Office of the Director (OD), Deputy Director for Public Health Science, Dr. David Fleming, and Associate Director for Minority Health, Dr. Walter W. Williams provide direct guidance and oversight to those OD staff responsible for facilitating and coordinating CDC's overall efforts in Indian country. In January 2002, CDC was pleased to welcome Ms. Pelagie ("Mike") Snesrud, RN (Mdewakanton Dakota) as CDC's Senior Tribal Liaison for Policy and Evaluation. Mike's office is located at CDC's Roybal Campus on Clifton Rd. (Atlanta), and she can be reached at 404-639-0432 or via e-mail at pws8@cdc.gov. She will lead efforts that relate to AI/AN policy, evaluation, and training. Among her priority activity areas are the following: CDC's Tribal Consultation Initiative; AI/AN cultural competency within CDC; recruitment/training/career development for AI/AN students; and partnerships with Tribal Colleges and Universities (TCUs). Mike will work closely with Dr. Ralph Bryan, CDC's Senior Tribal Liaison for Science and Public Health. Ralph remains in Albuquerque with the rest of the CDC and IHS National Epidemiology Program team (rrb2@cdc.gov) where he leads CDC/OD efforts that relate to AI/AN clinical, epidemiologic, and scientific activities. Among his priority activity areas are the following: IHS liaison activities and the CDC/ATSDR/IHS Senior Policy Workgroup; CDC collaborations with Tribal Epidemiology Centers; public health infrastructure and bioterrorism preparedness for Indian country, including Public Health Performance Standards activities; and partnerships with national organizations such as the Council of State and Territorial Epidemiologists (CSTE). Readers should feel free to contact Mike or Ralph regarding any CDC issues in Indian country.

Some new staff have arrived and expanded the program's capability to address new projects or maintain ongoing ones. Welcome to Ms. Lori deRavello who is assigned from CDC to the STD/Chlamydia team and arrived this week. Second, Dr. Ralph Groves is the new EIS Officer from CDC and arrived in August. He's just completed his residency training in family medicine. Next is Dr. Lauren Lewis who is the Preventive Medicine Resident assigned from CDC. Her one year training assignment is to learn public health policy and program management. Dr. John Redd is here to oversee the Hepatitis program. Also here is Ms. Yolanda Savage, Public Health Prevention Specialist, on assignment from CDC. Read more about her in this publication. Finally, Ms. Cecile Town is a contractor here to help coordinate the Hepatitis activities.


Ralph


Lauren


Yolanda


Cecile

Cancer Program Staff

Chronic Disease:
Nathaniel Cobb, Ben Muneta, Roberta Paisano
Cancer Control: Dave Espey
Reproductive Health: Leslie Randall
Tobacco Control: Lorene Reano

Infectious Disease:
James Cheek, Don Reece, Cheryl Mason
Hepatitis: John Redd, Cecile Town
Immunizations: Amy Groom
STD/Chlamydia: Laura Shelby, Lori de Ravello, Rachel Pacheco

Senior CDC/ATSDR Tribal Liaison: Ralph Bryan
EIS Officer: Ralph Groves
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Public Health Prevention Specialist: Yolanda Savage
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Data linkage con't.

"mis-identification" or "mis-classification" previously demonstrated in 5 previous linkage projects using IHS and cancer registry data. Mis-classification of race for AI/AN persons in these linkages ranged from 24% to 136% - levels of error that have an enormous impact on the cancer burden in AI/AN populations reported by these registries.

Table of Mis-identification and Mis-classification

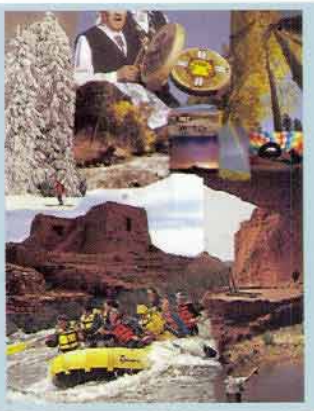
Study	Incidence (# cases) before match	Incidence (# cases) after match	Change
Oregon, Idaho, Washington (1996-97)	(332)	(412)	27%
Washington (1992-93)	153.5	267.5	74%
Minnesota (1988-93)	245.2	390.25	59%
California (1988-92)	89.6	211.0	136%
Puget Sound (1974-89)	(137)	(233)	70%

In September 2001, data from 8 of the 14 Surveillance, Epidemiology and End Results (SEER) program registries were linked with IHS patient registration data. The linkages increased the number of AI/AN persons with cancer by 24%. The error level in the registry data ranged from 5% to 94%. More recently, the CDC is funding a project to link IHS data with 25 state registries participating in the National Program of Cancer Registries (NCPR). Approximately 5 registries have been linked and preliminary results show substantial levels of misclassification. In both the SEER-IHS linkage the NPCR-IHS linkage, records of all persons who are currently mis-classified an non-Native will be corrected in the respective registries. At the end of the linkage project, we will have a more accurate picture of cancer incidence the AI/AN populations at the state, regional, and national levels. These linkages will be repeated at 2-3 year intervals as part of a continuous data quality improvement process focusing on correct reporting of cancer in the AI/AN population of the US.

It is important to note that tribal identification is not included in these linkages. If a specific tribe is interested in measures of cancer incidence in its community, a similar linkage between a tribal roster and state cancer registry can be arranged under the auspices of the tribal leadership.

When the linkages are completed, we will prepare a report summarizing the linkage and the cancer rates for AI/AN. These rates can then be used to inform cancer control activities, to prepare grant applications, and to advocate for increase funding for cancer prevention and control programs in Indian communities.

Finally, such linkages have the potential - and are being used - to improve other important databases as well, such as birth and death records, and other disease registries such as diabetes. As experience and comfort with these linkages grows, we should have improved data for influencing disease prevention and control programs for the population we serve.



Come visit us here in New Mexico!